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From Principle to Practice

Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)

Joint United Nations Programme on HIV/AIDS

UNAIDS

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From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)

Joint United Nations Programme on HIV/AIDS
UNAIDS
UNICEF • UNDP • UNFPA • UNDCP
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UNAIDS
Geneva, Switzerland
1999

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From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)

"With open heart,

Let's stand up and speak out to the world..."

Philly Bongole Lutaaya[1]

At the 1994 Paris AIDS Summit, 42 national governments declared that the principle of greater involvement of people living with or affected by HIV/AIDS (GIPA) is critical to ethical and effective national responses to the epidemic (see the complete text of the declaration at the end of this document, particularly Section IV.1). This is, therefore, the official position of these governments, which have committed themselves to supporting full involvement of persons living with or affected by HIV/AIDS (PWHAs)[2] in the "common response to the pandemic at all – national, regional and global – levels".

However, little has been done so far to make this principle a reality. Instead of being taken up by those responsible for national responses, GIPA has been most strongly promoted by individuals living with or affected by HIV/AIDS, often by "going public" about their serostatus in order to give a human face and voice to the epidemic.

In many places, several major constraints exist:

- GIPA is not reflected in national policies and programmes in any concerted or large-scale way, and there is an almost total lack of mechanisms permitting or encouraging PWHAs' experiences, perceptions and skills to be considered (much less utilized). This is partly because no major global, regional or national campaigns have yet been carried out to raise awareness and understanding of GIPA.
- Social, cultural and political environments, often characterized by high levels of denial, fear and stigmatization, are not conducive to the involvement of PWHAs.
- PWHAs are often in a difficult position, economically weak and having no structure that permits them to contribute to policy changes.
- Both PWHAs and existing AIDS Programme managers and staff need education and skill-building in order for GIPA to have its optimum impact.

[1] The Uganda musician Philly Lutaaya was the first African celebrity to disclose his HIV-positive status and to join the campaign against AIDS. An early advocate of "living positively" and eliminating stigma, he is considered one of the "fathers" of GIPA. Philly Lutaaya died in 1989.

[2] The Global Network of Persons Living with HIV/AIDS (GNP+) and The International Community of Women Living with HIV/AIDS (ICW) have officially adopted the acronym PWHA to designate people infected with or affected by HIV/AIDS. This includes people who are seropositive and the people who surround them (such as loved ones, parents and friends).

No single approach to implementing GIPA can be successful given these different obstacles, as well as particular local ones in different places. Nonetheless, sufficient experience has been gathered around the world to provide guidance on how GIPA can be effectively translated into action.

Defining GIPA

At its most basic, GIPA means two important things:

- recognizing the important contribution people infected or affected by HIV/AIDS can make in the response to the epidemic
- creating space within society for their involvement and active participation in all aspects of that response.

This contribution can be made at all levels, from the individual to the organizational, and in all sectors from the social and cultural to the economic and political. In particular, the Paris declaration emphasizes the role of networks of PWHAs and community-based organizations.

What do we mean by people living with or affected by HIV/AIDS (PWHAs)?

The original term used in the declaration, "people living with HIV/AIDS", has since been widened by broad consensus to the term "people living with or affected by HIV/AIDS" (PWHA). It is important to note that PWHA is not a single category of persons but a continuum. The continuum runs from individuals living with the symptoms of AIDS, on the one hand, to HIV-negative partners, family members and close friends of HIV-positive persons on the other.

What do we mean by "greater involvement"?

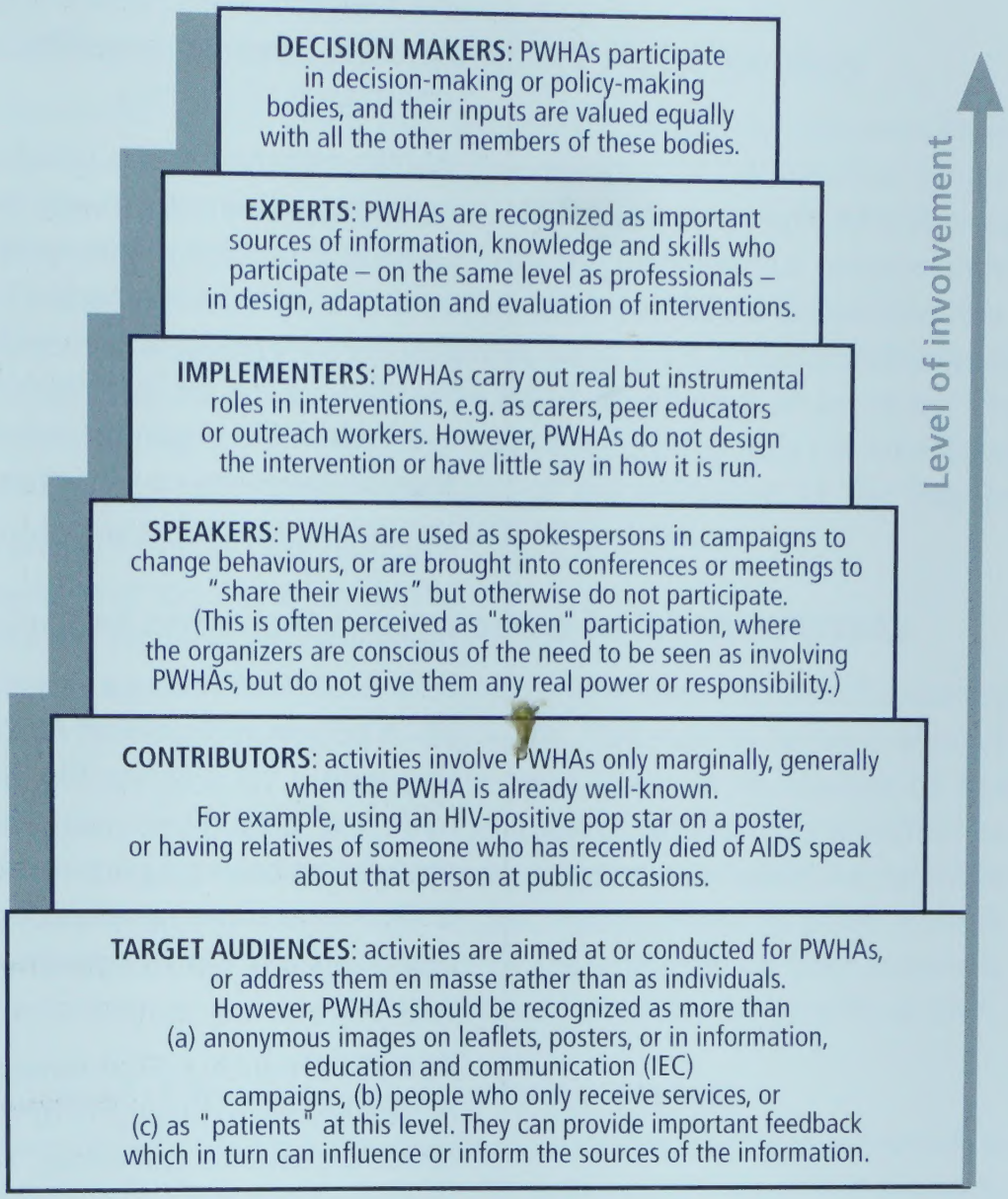
There is no substitute for direct experience, which can be considered a kind of expertise if accompanied by the ability to communicate well. At its most basic, therefore, greater involvement by PWHAs means creating a space for individuals to:

- use their experience of living with or being affected by HIV/AIDS in the greater response to the epidemic
- give a human face and voice to the epidemic in the minds of people not directly touched by it.

In an operational sense, this involvement may (and should!) include a variety of roles at many different levels. For instance, participation of PWHAs is already accepted to some degree at the international level in multilateral institutions and in regional and international conferences, at the national level in national AIDS programmes, and at local level in the community-based associations which often organize prevention, care and support activities. However, too often the roles open to PWHAs at all of these levels are limited to observer or educational

Figure 1. A pyramid of involvement by PWHAS

This pyramid models the increasing levels of involvement advocated by GIPA, with the highest level representing complete application of the GIPA principle. Ideally, GIPA is applied at all levels of organization.


DECISION MAKERS: PWHAs participate in decision-making or policy-making bodies, and their inputs are valued equally with all the other members of these bodies.
EXPERTS: PWHAs are recognized as important sources of information, knowledge and skills who participate – on the same level as professionals – in design, adaptation and evaluation of interventions.
IMPLEMENTERS: PWHAs carry out real but instrumental roles in interventions, e.g. as carers, peer educators or outreach workers. However, PWHAs do not design the intervention or have little say in how it is run.
SPEAKERS: PWHAs are used as spokespersons in campaigns to change behaviours, or are brought into conferences or meetings to "share their views" but otherwise do not participate. (This is often perceived as "token" participation, where the organizers are conscious of the need to be seen as involving PWHAs, but do not give them any real power or responsibility.)
CONTRIBUTORS: activities involve PWHAs only marginally, generally when the PWHA is already well-known. For example, using an HIV-positive pop star on a poster, or having relatives of someone who has recently died of AIDS speak about that person at public occasions.
TARGET AUDIENCES: activities are aimed at or conducted for PWHAs, or address them en masse rather than as individuals. However, PWHAs should be recognized as more than (a) anonymous images on leaflets, posters, or in information, education and communication (IEC) campaigns, (b) people who only receive services, or (c) as "patients" at this level. They can provide important feedback which in turn can influence or inform the sources of the information.
Level of involvement

functions. Figure 1 provides a model of ways in which people living with or affected by HIV/AIDS can play a much wider range of roles.

It should be noted that the model does not include an important part of GIPA: the efforts of individuals at a personal level. Although not part of any formal arrangement or structure, a significant portion of the worldwide response to HIV/AIDS is the work of individual people caring – in many different ways – for their seropositive family members and friends. It is also the work of individuals who, by "living positively" or openly interacting with PWHAs, act as examples to others, thereby countering both the denial and stigma that attend the epidemic in many communities.

It should be stressed, however, that GIPA does not mean necessarily disclosing one's serostatus. Although there should be nothing to stop PWHAs being open about their serostatus to their colleagues and community, PWHAs also have the right to choose to be involved without making their serostatus public. In other words, GIPA cannot be reduced to "no visibility = no involvement".

Why involve PWHAs?

There are many reasons why GIPA is so important to the response to the epidemic. At the social level, publicly acknowledged involvement helps reduce stigma and discrimination, and sends a signal to society regarding acceptance and recognition of the importance of PWHAs.

Within organizations, involvement can be a powerful tool for breaking down barriers, whether subjective or objective. Organizations are made up of individuals, and individuals who are neither infected nor affected by HIV/AIDS often have preconceived ideas which are seriously misinformed about PWHAs. Not surprisingly, these ideas can be reflected in organizational policies or practices, even when the organizations are active participants in the response such as government ministries, international agencies or NGOs.

Discrimination against PWHAs is widespread, though it is often subtle or hidden, and is not even always consciously recognized as such by those who discriminate. Working with seropositive individuals on a daily basis, and having a name and face to associate with the concept of "a person with HIV or AIDS" – where previously the association was with a virus or terrible disease – helps people overcome their fears and prejudices, and change their perception of PWHAs. By providing a basis for partnership, mutual respect and understanding, GIPA breaks down simplistic concepts of "service giver" (that is, the person who is not HIV-positive) and "service receiver" (the person who is).

As well as reducing discrimination, GIPA can reinforce an organization or activity by exposing it to the unique perspectives that PWHAs' direct experience can bring. This reinforcement can be at the level of general morale and team-building, or it may include substantive improvements in the way an organization actually works. For instance, PWHAs can perform a valuable support function in an organization or activity that has hired or designated "AIDS workers" such as public health educators, clinicians, psychologists and social workers. Whereas workers often receive little emotional or practical support for their AIDS prevention and education activities, PWHAs can give them the benefit of their knowledge, help boost their confidence, and reassure them of the value of their contribution.

Finally, GIPA also has important benefits for PWHAs as individuals. Experience indicates that this kind of involvement – especially if it comes after a period of feeling hopeless and depressed – build up a person's motivation. PWHAs (like everyone else) need to feel valued for what they can offer. Involvement gives HIV-positive people support and can empower them in ways that increases the value of their contribution to the organization or activity.

Challenges to implementing GIPA at higher levels

As well as promising a range of potential benefits, GIPA faces a number of challenges, particularly at the higher levels of organizations. These include:

Difficulty of acknowledging HIV status publicly

Openness about one's own serostatus to family, community or workplace is more difficult in some countries or cultures than others. In some cases, precautions are needed to protect people who disclose their positive serostatus, since this can create serious repercussions for them in their jobs and within their families and communities. Discrimination shows up in different ways, from almost invisible types of social behaviour on the one hand, to physical violence on the other. Similarly, PWHAs' fears may range from purely personal (and not always accurate) perceptions of discrimination all the way to objectively based fears of rejection and violence.

Lack of organizations prepared to involve PWHAs

There are currently too few organizations involving or collaborating with PWHAs in their day-to-day work. This may be because of a lack of awareness or information among those in charge of the organizations, or it may be because of active discrimination or unconscious prejudice. Lack of awareness or information is a particular problem within the private sector: management is often entirely unaware of the possible impact of the epidemic on their economic performance, and does not understand the potential benefits of GIPA.

Lack of skills and preparation for PWHAs

Lack of skills can create a variety of obstacles. First, not everybody is born with the natural capacity to speak about issues like sexuality and health – it is a skill that most often has to be learned. Secondly, facing a possibly hostile or uncomprehending environment can lead to the "burnout" syndrome unless a person is either very strong to start with or has been through an empowerment process. For both of these reasons, communication and personal empowerment counselling should be part of a generic training package for people participating in GIPA initiatives. As well, such training must be reinforced by ongoing support for PWHAs if their effectiveness is to remain high and their motivation strong.

Thirdly, special orientation or job-specific training may be required to compensate for the lack of particular technical skills or knowledge. This point begs the question of appropriate hiring. Clearly, hiring people solely because they are HIV-positive, and without regard to their particular skills and capabilities, is tokenistic; it puts the emphasis on the virus rather than on the person and his or her character and abilities. At the same time, those responsible for hiring should recognize the value of the PWHA's experience-based expertise and include this in their decision-making.

Lack of proper conditions for HIV-positive people within organizations

Organizations may not have a satisfactory policy for the employment or involvement of people living with HIV and AIDS. They may also lack the sort of environment and facilities that are necessary or helpful to seropositive people such as health care facilities, medical insurance and psychosocial support.

Questions of sustainability

It has to be recognized that HIV-positive people may fall sick because of their infection and its related illnesses, and that some of them will die. This poses an obstacle particularly to the private sector, in which employers may feel threatened by reduced working hours due to illness and loss of skilled manpower due to premature death.

Obviously, the risk of falling sick or dying exists for all employees or members of organizations, whatever their serostatus; the odds are greater (and certainly more highly publicized) for people living with HIV/AIDS than for many other groups of people. This issue should not be avoided, since it is real. Instead, it has to be discussed in order to anticipate difficulties with sustainability.

Responses

Experience has shown that there are a variety of effective ways to deal with the above-mentioned obstacles to implementing or improving GIPA initiatives.

Document existing experiences and build on lessons learned

The results of many successful GIPA-related interventions have been published. These are very useful in helping explain the concept and its benefits, as well as providing concrete examples of how interventions can be implemented. Prominent examples include the following:

- *The AIDS Service Organisation (TASO), Uganda.* Much of the organizing drive which created and shaped TASO was provided by a woman whose husband had died of AIDS. Her major "competence" was not formal training but rather her strong motivation, which resulted from her personal experience of caring for a person with AIDS and her exposure to HIV-related stigma. From its beginnings in 1988, TASO developed into one of the most prominent and innovative groups in the AIDS field internationally. (For more information, see Hampton J. *Living positively with AIDS* available from Teaching Aids at Low Cost (TALC), London, United Kingdom.)
- *Asia Pacific Network of People living with HIV/AIDS (APN+).* This advocacy organization had its beginnings in February 1994 when 42 PWHAs from 8 countries in the Asia Pacific region met

in Kuala Lumpur, Malaysia. They agreed to lobby for the betterment of PWHAs in the region, and to work against stigma and discrimination. APN+ now includes 10 countries. (See the Internet location http://www.hivnet.ch/gnp/asp1.html)

- *The "UNV Support to People Living with HIV/AIDS" Project.* This is a collaborative pilot project between the United Nations Development Programme (UNDP), United Nations Volunteer Programme (UNV), UNAIDS and the Network of African People Living with HIV and AIDS (NAP+). Currently in its second year of operation in Malawi and Zambia, and soon to be extended to Asia, the project recruits, trains and supports HIV-positive persons whom it places as National UN Volunteers in various host institutions. (See *Enhancing the Greater Involvement of People Living with HIV and AIDS (GIPA) in sub-Saharan Africa: A UN Response: How far have we gone?* UNDP, in press.)

Create a more enabling and supportive environment

GIPA cannot be fully effective or widely applied unless there are changes in wider society, with discrimination and stigma transformed into tolerance and acceptance by information and awareness campaigns. Political, traditional and religious leaders have a major role to play by bringing about these social changes. Parliamentarians, for example, can help draw up antidiscrimination laws and national policies on AIDS and the workplace. At a different level, law enforcement officers in some societies can do much to curtail physical violence and other forms of intimidation against PWHAs. Such official activities by these prominent individuals, as well as less formal participation in local initiatives dealing with AIDS in their communities, can have a considerable impact on overall social attitudes to people living with or affected by HIV/AIDS.

Social change must be matched by institutional change in international, national, or local organizations. A variety of initiatives (see below) can be taken to enable HIV seropositive individuals to take part in the response to the epidemic. However as mentioned under the challenges, it is the absolute right of people to choose not to disclose their serostatus or their relationship to somebody infected by HIV.

Understand the needs and worries of the private sector

In parts of the world hardest hit by the epidemic, many businesses have significant numbers of employees infected or affected by HIV/AIDS. For this reason, the private sector has both a strong interest and a major role to play in the response to the epidemic. It is therefore extremely important for businesses and their leaders to understand that, while AIDS among employees and the general public can affect productivity and profitability, constructive measures can be taken that will mitigate such adverse effects. GIPA is at the core of such measures.

A crucial message for business leaders is that PWHAs can be ideal partners to plan for comprehensive prevention, care and support interventions at the workplace. For instance, peer education by someone infected with HIV or someone "with AIDS in the family" can be part of a corporate action plan.

Other GIPA-related activities which can be done or supported by the private sector include: posting advertisements stating that HIV-positive people are welcome to apply for employment with the company; providing counselling services at the workplace; having senior management collaborate regularly and publicly with PWHAs in creating HIV/AIDS workplace plans; providing training and adapting workload for PLWHAs involved in the workplace plan. All such activities have their costs and must be budgeted for, but none is highly expensive and their cost-benefit ratio is generally very favourable.

Anything that might be seen as "preferential hiring" is potentially controversial. In the private sector – as much or more so than in the public or nongovernmental sectors – hiring should be mainly based on qualification for any given job. However, this should not be used as a justification for refusing to hire a PWHA who can (a) adequately fill a specific job's requirements and (b) provide the important benefits of GIPA.

Experience shows that PWHAs very often have an extremely strong motivation which can justify their being hired before they have all the technical expertise required by the job (although, clearly, this expertise has to be acquired eventually, either through training or on-the-job experience). Examples can be found in the work of many parents and partners of HIV-positive people: without any training in administration or management, and with extremely limited resources, these "HIV-affected" people have been able to organize and run thousands of support and advocacy groups around the world. Such strong motivation, which can also ignite or enhance the personal charisma of certain individuals, can be a valuable resource when channelled by GIPA into other organizations and activities.

Training and ongoing support for individuals

GIPA activities cannot count indefinitely on individuals' motivation or charisma, however. It is of utmost importance to provide training and support for PWHAs actively involved in the response to the epidemic.

International organizations and associations for persons living with HIV/AIDS can help to provide a generic package for those individuals wanting to disclose their personal relation to AIDS. As well as training for the specific job, GIPA training packages for PWHAs should include:

- personal empowerment
- communication and presentation skills
- HIV/AIDS knowledge

- legal aspects of HIV/AIDS
- skills for organizing and conducting policy dialogue.

If the employee is to take on any administrative responsibility for GIPA activities, training should also include the basics of programme planning and monitoring.

Training and orientation for organizations

It is equally important that organizations – including top executives as well as supervisory staff – receive the benefit of training and orientation to the precepts of GIPA. Among other issues, host organizations must be aware that by hiring a person living with HIV they take on an added responsibility with ethical consequences. This responsibility is not an difficult one to assume, however, with proper preparation.

This training should include at least three components:

- challenges and benefits of instituting GIPA and recruiting PWHAs, including policy formulation
- responsibilities of, and implementation strategies for, host organizations
- lessons learned from existing GIPA efforts (best practice).

All of this should be aimed at creating supportive environments as well as organizational structures which allow full application of GIPA at the highest levels.

Declaration of the Paris AIDS Summit 1 December, 1994

(Note: statements directly related to GIPA have been italicized)

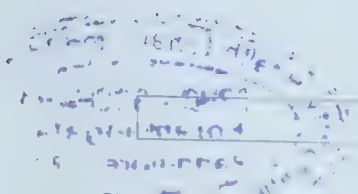
We the Heads of Government or Representatives of the 42 States assembled in Paris on 1 December, 1994:

I. MINDFUL that the AIDS pandemic, by virtue of its magnitude, constitutes a threat to humanity, that its spread is affecting all societies that it is hindering the social and economic development, in particular of the worst affected countries, and increasing disparities within and between countries, that poverty and discrimination are contributing factors in the spread of the pandemic, that HIV/AIDS inflicts irreparable damage on families and communities, that the pandemic concerns all people without distinction but that women, children and youth are becoming infected at an increasing rate, that it not only causes physical and emotional suffering, but is often used as a justification for grave violations of human rights,

MINDFUL ALSO that obstacles of all kinds – cultural, legal, economic and political – are hampering information, prevention, care and support efforts, that HIV/AIDS prevention and care support strategies are inseparable, and hence must be an integral component of an effective and comprehensive approach to combating the pandemic, that new local, national and international forms of solidarity are emerging, involving in particular people living with HIV/AIDS and community based organizations,

II. SOLEMNLY DECLARE our obligation as political leaders to make the fight against HIV/AIDS a priority, *our obligation to act with compassion for and in solidarity with those with HIV or at risk of becoming infected, both within our societies and internationally, our determination to ensure that all persons living with HIV/AIDS are able to realize the full and equal enjoyment of their fundamental rights and freedoms without distinction and under all circumstances, our determination to fight against poverty, stigmatization, and discrimination, our determination to mobilize all of society – the public and private sectors, community-based organizations and people living with HIV/AIDS – in a spirit of true partnership*, our appreciation and support for the activities and work carried out by multilateral, intergovernmental, nongovernmental and community-based organizations, and our recognition of their important role in combating the pandemic, our conviction that only more vigorous and better coordinated action worldwide, sustained over the long term – such as that to be undertaken by the joint and co-sponsored United Nations programme on HIV/AIDS – can halt the pandemic,

III. UNDERTAKE IN OUR NATIONAL POLICIES TO *protect and promote the rights of individuals, in particular those living with or most vulnerable to HIV/AIDS, through the legal and social environment, fully involve nongov-*



ernmental and community-based organizations as well as people living with HIV/AIDS in the formulation and implementation of public policies, ensure equal protection under the law for persons living with HIV/AIDS with regard to access to health care, employment, travel, housing and social welfare, intensify the following range of essential approaches for the prevention of HIV/AIDS:

- promotion of and access to various culturally acceptable prevention strategies and products, including condoms and treatment of sexually transmitted diseases,
- promotion of appropriate prevention education, including sex and gender education, for youth in school and out of school,
- improvement of women's status, education and living conditions,
- *specific risk-reduction activities for and in collaboration with the most vulnerable populations, such as groups at high risk of sexual transmission and migrant populations,*
- the safety of blood and blood products,
- strengthen primary health care systems as a basis for prevention and care, and integrate HIV/AIDS activities into these systems, so as to ensure equitable access to comprehensive care,
- make available necessary resources to better combat the pandemic, including adequate support for people infected with HIV/AIDS, nongovernmental organizations and community-based organizations working with vulnerable populations.

IV. ARE RESOLVED TO STEP UP THE INTERNATIONAL COOPERATION THROUGH THE FOLLOWING MEASURES AND INITIATIVES. We shall do so by providing our commitment and support to the development of the joint and co-sponsored United Nations programme on HIV/AIDS, as the appropriate framework to reinforce partnerships between all involved and give guidance and worldwide leadership in the fight against HIV/AIDS. The scope of each initiative should be further defined and developed in the context of the joint and co-sponsored programme and other appropriate fora:

1. *Support a greater involvement of people living with HIV/AIDS through an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS and community-based organizations. By ensuring their full involvement in our common response to the pandemic at all – national, regional and global – levels, this initiative will, in particular, stimulate the creation of supportive political, legal and social environments.*

2. Promote global collaboration for HIV/AIDS research by supporting national and international partnerships between the public and private sectors, in order to accelerate the development of prevention and treatment technologies, including vaccines and microbicides, and to provide for the measures needed to help ensure their accessibility in developing countries. This collaborative effort should include related social and behavioural research.

3. Strengthen international collaboration for blood safety with a view to coordinating technical information, proposing standards for good manufac-

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turing practice for all blood products, and fostering the establishment and implementation of cooperative partnerships to ensure blood safety in all countries.

4. Encourage a global care initiative so as to reinforce the national capability of countries, especially those in greatest need, to ensure access to comprehensive care and social support services, essential drugs and existing preventive methods.

5. Mobilize local, national and international organizations assisting as part of their regular activities children and youth, including orphans, at risk of infection or affected by HIV/AIDS, in order to encourage a global partnership to reduce the impact of the HIV/AIDS pandemic upon the world's children and youth.

6. Support initiatives to reduce the vulnerability of women to HIV/AIDS by encouraging national and international efforts aimed at the empowerment of women: by raising their status and eliminating adverse social, economic and cultural factors; by ensuring their participation in all the decision-making and implementation processes which concern them; and by establishing linkages and strengthening the networks that promote women's rights.

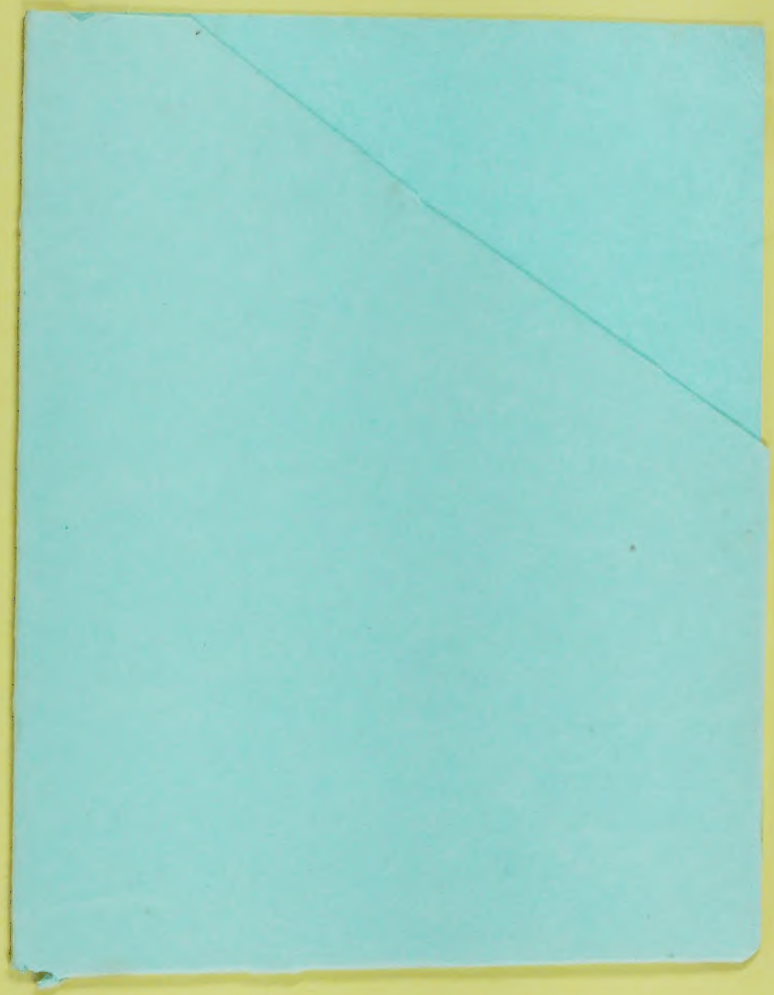
7. *Strengthen national and international mechanisms that are concerned with HIV/AIDS related human rights and ethics, including the use of an advisory council and national and regional networks to provide leadership, advocacy and guidance in order to ensure that non-discrimination, human rights and ethical principles form an integral part of the response to the pandemic.*

We urge all countries and the international community to provide the resources necessary for the measures and initiatives mentioned above.

We call upon all countries, the future joint and co-sponsored United Nations programme on HIV/AIDS and its six member organizations and programmes to take all steps possible to implement this Declaration in accordance with other multilateral and bilateral aid programmes and intergovernmental and nongovernmental organizations.

Countries which were represented at the Paris Summit and signed the Declaration:

Argentina, Australia, Bahamas, Belgium, Brazil, Burundi, Cambodia, Cameroon, Canada, China, Côte d'Ivoire, Denmark, Djibouti, Finland, France, Germany, India, Indonesia, Italy, Japan, Mexico, Morocco, Mozambique, Netherlands, Norway, Philippines, Portugal, Romania, Russian Federation, Senegal, Spain, Sweden, Switzerland, United Republic of Tanzania, Thailand, Tunisia, Uganda, United Kingdom, United States of America, Viet Nam, Zambia, Zimbabwe.



The Joint United Nations Programme on HIV/AIDS (UNAIDS) is the leading advocate for global action on HIV/AIDS. It brings together seven UN agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO) and the World Bank.

UNAIDS both mobilizes the responses to the epidemic of its seven cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV on all fronts: medical, public health, social, economic, cultural, political and human rights. UNAIDS works with a broad range of partners – governmental and NGO, business, scientific and lay – to share knowledge, skills and best practice across boundaries.

Produced with environment-friendly materials

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